

Webinar: Registries

Note: This webinar took place on 8 February 2018. You can find a video recording and the presentations used during the webinar below.

Webinar introduction

A patient registry is an organised system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes (source). This webinar discusses the use and utility of registries from the perspectives of public health and of patient communities.

Webinar recording

Speakers:

- Prof. Klaus Berger, University of Münster
- Lara Bloom, Ehlers-Danlos Society
- Prof Wolf See, University of Bonn, Bayer, EUPATI

Webinar presentations

Presentation of Prof. Klaus Berger

Presentation of Lara Bloom